

SMICS

Southern Melbourne
Integrated Cancer Service

Victorian and Tasmanian Youth Cancer Network Project

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Prepared for: SMICS Governance Committee

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28th December 2011

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Executive Summary

Introduction

There is growing recognition, both in Australia and overseas, that existing health care structures and approaches are contributing to relatively poor survival rates among adolescent and young adult (AYA) cancer patients (aged 15–25 years). AYA cancer survival has become a public health issue across the globe over recent years. There is growing recognition in Australia that the specific needs of AYA cancer patients are not being met by existing services.

The Victorian and Tasmanian Youth Cancer Network Project (VTYCN) has been established to support changes that will aim to improve the outcomes for AYA's with cancer in Victorian and Tasmania. This will occur through improved delivery and coordination of services, support and care. The VTYCN project is supported by funding from the Australian Government under the Youth Cancer Network (YCN) program.

The VTYCN project model builds on the OnTrac@PeterMac program, as well as working with the Integrated Cancer Services and oncology units throughout Victoria and Tasmania.

Project Objective

Southern Melbourne Integrated Cancer Service (SMICS) focused on areas that sought to address issues identified in AYA cancer care in southern Melbourne. The key priority areas identified for service improvements for AYA's included:

- establishment of a sustainable model of care and referral pathway that promote optimal care and provides comprehensive psychosocial support
- facilitation of workforce development and support through education and training by developing and strengthening linkages between local clinicians and OnTrac@PeterMac
- professional development opportunities will also be explored to address identified gaps and increase local capacity.

Background

The Youth Cancer Network is a federal government initiative which aims to improve delivery and coordination of services, support and care for AYA with cancer. Fifteen million dollars has been allocated over the two years to achieve these aims. The program is being coordinated and administered by CanTeen, the peak support and advocacy body for young people with cancer.

Project Methodology

A medical record audit was completed in each of the member health services to identify patterns of referral for AYA's with cancer in the SMICS catchment.

Mapping of services available to AYA's with a cancer diagnosis within the SMICS region identified service gaps, allowing further scoping of the larger region to include appropriate services, such as *headspace Southern Melbourne*, to assist in providing the psychosocial care for an AYA with cancer.

The stakeholders were identified as participants in the care of AYA's. These stakeholders were subsequently trained in skills to provide appropriate screening and assessment for

AYA's at diagnosis under the guidance of onTrac@PeterMac. Further education forums were also delivered to cancer health care professionals more broadly. Participants of these training and education sessions were asked to provide feedback by way of questionnaire.

The Project provided the opportunity to develop and strengthen linkages between these local clinicians and onTrac@PeterMac through extensive networking and influencing and supporting AYA referrals to this service.

Summary of Findings

The medical record audit to review AYA cancer referral pathways in the SMICS catchment was successful in providing data and information about patterns of referral for AYA's with cancer.

Participants of the *You Can* training and the *fertility education forum* indicated a high level of satisfaction with the project. The results from the questionnaires from this training indicated that all of the education aims were met, resulting in a greater understanding of the significantly different AYA health care needs to those of children and adults with cancer.

Cancer service mapping within the SMICS catchment undertaken by SMICS in 2009, was used as a guide to list all service provisions available within the health setting, and enabled the project to scope outside the health services to include other services such as headspace Southern Melbourne to assist in the delivery of age appropriate care to this group.

Since the introduction of the YCN project there have been nine referrals from SMICS health services to the onTrac@PeterMac secondary consultation service.

Next Steps

- SMICS plan to liaise with onTrac@PeterMac to offer further training to project stake holders, and individual training to new health professionals
- SMICS will incorporate AYA training into its Supportive Care calendar
- SMICS will continue to offer support in sustaining the relationships with local health professional and other organisations that are skilled in AYA care
- SMICS will continue to provide this guidance and continue to influence AYA referrals to the onTrac@PeterMac secondary consultation meeting
- As part of the Supportive Care portfolio SMICS will monitor the referral process between local health sites psychosocial support access, inclusive of headspace
- As part of the Supportive Care portfolio SMICS will audit results of supportive care screening including You Can screening

Introduction

Internationally and nationally it is recognised that existing health care structures and approaches have not addressed the relatively poor survival rates among adolescent and young adult (AYA) cancer patients (aged 15–25 years). AYA cancer survival has become a public health issue across the globe over recent years. There is growing recognition in Australia that the specific needs of AYA cancer patients are not being met by existing services. Improvements in survival and outcomes for AYA's lag significantly behind the advances that have been achieved for both children and older adults over the past 30 years.

In 2010, the Clinical Oncological Society of Australia (COSA) convened a workshop which brought together participants and key stakeholders with an interest in the treatment of AYA's with cancer to identify ways to address the issues.

As a result of the work of individual health services, the states and that which has occurred at a national level, the federal government provided funds for the YCN project. The YCN aims to improve the delivery and coordination of services including; improved access to clinical trials, support, and specialised psychosocial care for AYA's with cancer. The program is being coordinated and administered by CanTeen, the peak support and advocacy body for young people with cancer.

The Victorian and Tasmanian Youth Cancer Network Project (VTYCN) project has been established to support changes that will aim to improve the outcomes for AYAs with cancer in Victoria and Tasmania. The VTYCN project model builds on the OnTrac@PeterMac program, as well as working with the Integrated Cancer Services and oncology units throughout Victoria and Tasmania.

This Project is aligned with the *National Service Delivery Framework for Adolescent and Young Adults with Cancer, 2009*¹. Victoria is well placed to develop an integrated service for AYA's with cancer. The state government has committed to the establishment of a state-wide cancer service in Victoria to provide direct care, specialist education support resources and secondary advice to services managing AYA patients with cancer. The *Victorian Cancer Action Plan (VCAP) 2008 – 2011*² has set specific AYA targets and milestones including:

- *By 2010 we aim to have an additional 10% of those adolescents and young adults at highest risk of poor outcomes enrolled in appropriate clinical trials*
- *By June 2012 we will develop and implement a comprehensive service for adolescents and young adults with cancer.*

Other aims of the VCAP 2008-2011 is to expand the already existing onTrac@PeterMac state-wide service for AYA's with cancer, to facilitate access to appropriate clinical and psychosocial follow-up and care. onTrac@PeterMac will provide secondary consultations and assistance with care planning. Other aims include the development of referral pathways for AYA's, implementation of clinical protocols, and providing additional education and training to help staff better responds to the needs of AYA's with cancer.

The Southern Melbourne Integrated Cancer Service (SMICS) is one of nine Integrated Cancer Services (ICS) established by the Victorian Government in 2004 to support the implementation of the VCAP 2008-2011 for Victoria. SMICS incorporates the four major health providers in southern Melbourne: Alfred Health, Peninsula Health, Cabrini Health

and Southern Health and aims to support improvements in the integration and coordination of cancer care.

Project Objective

As part of VCAP 2008-2011 and the National Service Delivery Framework for AYA's with Cancer, SMICS focused on areas that sought to address issues identified in AYA cancer care in southern Melbourne. The key priority areas identified for service improvements for AYA's included:

- establishment of a sustainable model of care and referral pathway that promote optimal care and provides comprehensive psychosocial support
- facilitation of workforce development and support through education and training by developing and strengthening linkages between local clinicians and OnTrac@PeterMac
- professional development opportunities will also be explored to address identified gaps and increase local capacity.

Project methodology

Medical record audit

SMICS firstly reviewed AYA cancer referral pathways, in order to provide data and information about patterns of referral for AYA's with cancer in the SMICS catchment. This was carried out by way of a hospital medical record audit, using Survey Monkey software.

The patient cohort for the audit was those AYA's, aged 15-25 years, diagnosed with a cancer during the 2009 calendar year. The aim of auditing this age group was to identify current referral practices across the SMICS region. This activity also provided a good overview of any local services available and offered to AYA's, and highlighted the local key health professionals involved in an AYA's care.

To optimise data collection, the SMICS Cancer and Information Analyst identified AYA patients with a diagnosis of cancer within the specified timeframe and contacted the Health Information Manager at each of the participating health services specifically: Alfred Health, Southern Health, Peninsula Health, and Cabrini Health.

This process resulted in the identification of 79 patients who appeared to be eligible for inclusion in the audit at these four health services. Each medical record was examined and of the 79, only 37 patients were identified as suitable. Patients who had a hospital admission in 2009 whose primary cancer diagnosis was prior to 2009, those who were treated in a paediatric setting, and those that only required one visit to a specialist and did not require further treatment (e.g. surgical removal of melanoma), were excluded from the audit. To increase the numbers for the region, a decision was made to also include patients diagnosed with a cancer toward the end of 2008, but who received the majority of their treatment in 2009.

The survey/audit

The SMICS medical record audit was carried out in the member health services and the data was entered directly into the survey tool by the SMICS AYA project officer.

No identifying data was entered into the survey, so each medical record was assigned a number and the survey responses were numbered sequentially. A separate Excel spreadsheet was developed to enable identification of the medical record should clarification be required.

Identification of stakeholders

The stakeholders were identified through the medical audit as key health professional participants in the care of AYA's, or selected based on their engagement with Supportive Care Groups at each member health service. There were 17 key health professionals including psychology, social work and nursing.

Education and training

***You Can* training**

SMICS organised an AYA training and education session for stakeholders, providing them with the skills to provide appropriate screening and assessment for AYA's at diagnosis. The onTrac@PeterMac team delivered this training using the '**You Can**' *Adolescent and Young Adult Oncology Psychosocial Care Manual*⁸ recommended as best practice care for AYA cancer patients. The 17 health professionals undertook specialised training in using the **AYA Oncology Screening Tool** and **AYA Oncology Care Plan**. Along with providing specialised AYA education, this session also introduced stakeholders to the onTrac@PeterMac service.

Questionnaires were distributed to each participant at the beginning of the education session. The stakeholder was asked to evaluate the delivery and relevance of this session, using 'Poor', 'Adequate', 'Good' and 'Excellent'. The questionnaires were collected at the end of the session, and collated by the VTYCN Education Officer for evaluation.

Post this training, SMICS proceeded to deliver information sessions throughout the SMICS public health services to discuss both the Youth Cancer Network project and onTrac@PeterMac service, and provide awareness of the specialised needs of AYA's. The importance of referring to one of the locally AYA trained stakeholders when identifying an AYA was a crucial part of the information session. A list of the stakeholders from each health site was distributed. Information sessions were delivered to all chemotherapy day units, radiotherapy departments, oncology inpatient wards, some oncology outpatient departments (including surgical clinics), and some dedicated cancer tumour stream clinics (e.g., haematology service, breast care nurses, clinical trials unit).

Fertility education forum

A fertility education forum was carried out as a pilot project within SMICS public member hospitals, and was delivered by the Victorian Assisted Reproductive Treatment Authority (VARTA). This forum was piloted to increase health care professionals awareness of fertility outcomes for young patients, and to encourage these professionals to offer timely and full discussion of risks, fertility preservation options and related issues essential for AYA's with cancer. The forum was complemented by a SMICS developed resource on

'Information on Fertility and Cancer' including a list of local contacts for the health care professionals use.

An invitation was sent to the three SMICS public member hospitals cancer services, resulting in this education forum being delivered to 70 health care professionals. Attendees included those from allied health disciplines, pharmacists, pastoral care, nurses, and doctors. Questionnaires were distributed to each health care professional at the beginning of the education session. Participants were asked to evaluate the delivery and relevance of this session, using 'Poor', 'Adequate', 'Good' and 'Excellent'. The questionnaires were collected at the end of the session for collation by the VTYCN Education Officer for evaluation.

Mapping services

In 2009 SMICS undertook a cancer *service mapping project*⁴ within the SMICS catchment. The mapping identifies all services available within the each health service which enables the identification of gaps and opportunities for improving service coordination. Through interviews with the AYA project key stakeholders it appears there has been no change to services provided within each health service since 2009 that will affect the care of AYA's with cancer. This mapping was used as a guide to what was and what was not available to AYA's at each SMICS public member health service.

Acknowledging that each health service differs in services provided, the Project provided the opportunity to further scope other service provisions outside these health settings in southern Melbourne, and meet with other appropriately aged and equipped health care providers to assist in the delivery of care to this age group. This occurred through face to face meetings to discuss the project, and enquire to whether their service is appropriate to help meet the needs of AYA's with cancer.

Developing and strengthening linkages between local clinicians and OnTrac@PeterMac

Identification of stakeholders provided the opportunity to network extensively with local clinicians. This engagement allowed/enabled the promotion of onTrac@PeterMac services. This input has help build relationships between these providers, and assisted in guiding and influencing referral and presentation of local AYA's at the onTrac@PeterMac secondary consultation meetings.

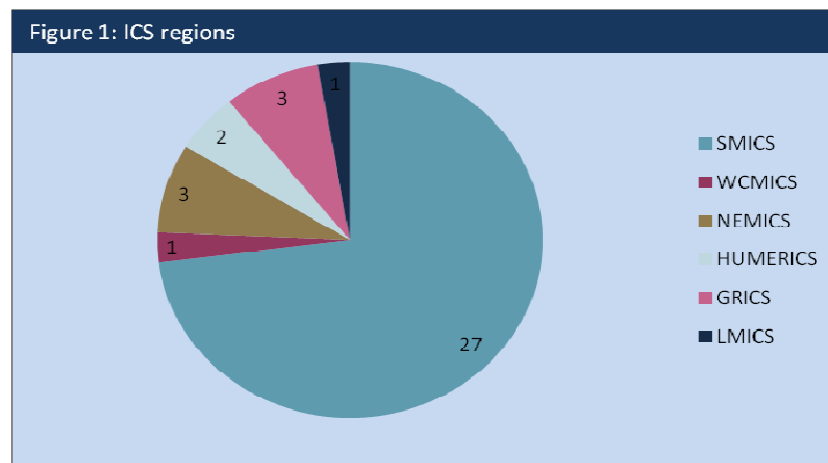
Project Discussion

Medical record audit findings

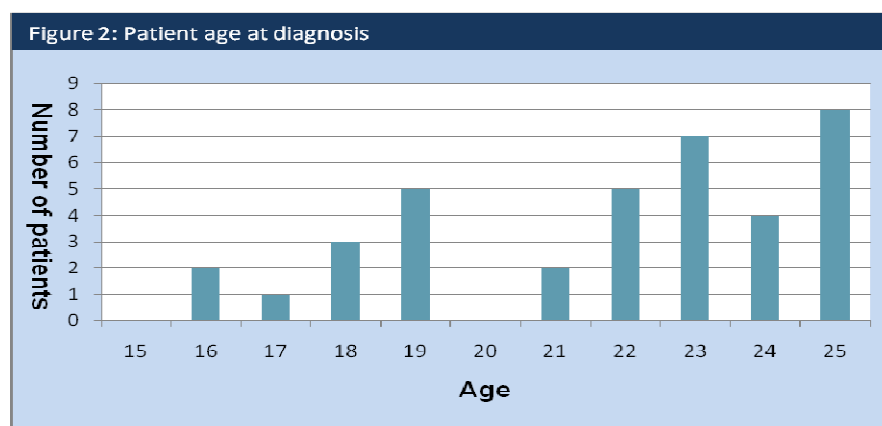
The findings of each individual AYA from each individual SMICS member health service have been collated to highlight the common themes for AYA's in the SMICS catchment. This was also useful to identify referral pathways for AYA's retrospectively.

Demographics

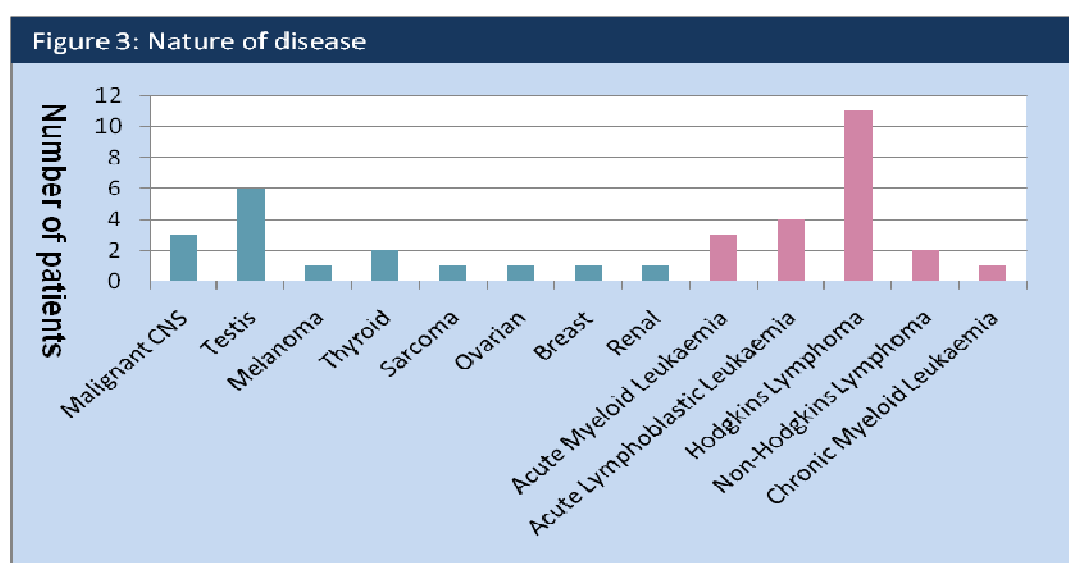
Figure 1 provides a summary of the ICS region each patient resided within. Over two thirds of patients reside in the SMICS region.



The age range of the patients included in the audit was 15 to 25. The majority of patients were aged 22 to 25 years old at diagnosis (figure 2). Twenty-five patients were male, while 12 were female



Of the 37 patients with a cancer diagnosis in 2009, 16 patients were diagnosed with a solid tumour cancer (blue), whilst 21 were diagnosed with a haematological malignancy (pink) (figure 3). Hodgkins lymphoma was the most common diagnosis.



Identified referral pathways

Figure 4 highlights the length of time the patient first experienced symptoms of their disease, to seeking initial medical advice. Approximately half of the patients were seen to seek medical advice within 0-2 weeks (majority of whom were diagnosed with acute leukaemia's) from first experiencing symptoms, whilst the other half sought medical advice from 2 weeks onwards, to 6 months.

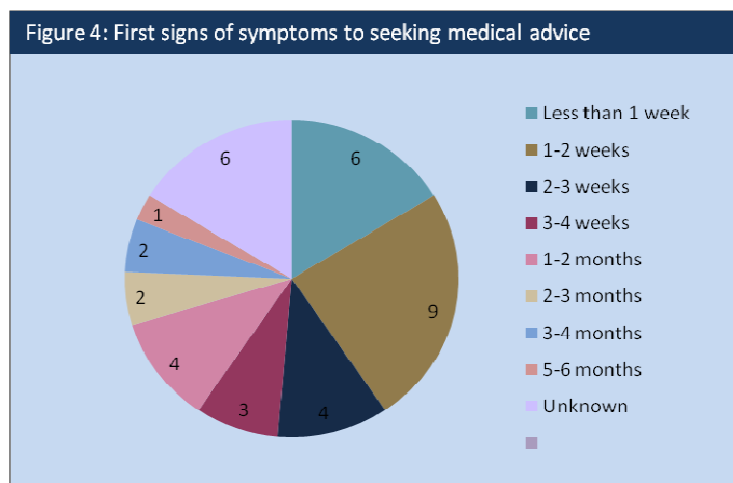


Figure 5 shows that for all medical records audited, all patients had a medical appointment with a clinician within two weeks from the time a cancer diagnosis was first suspected.

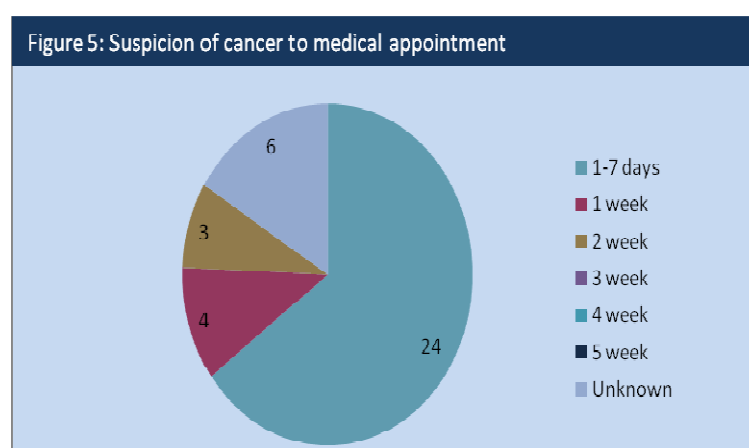


Figure 6 demonstrates less than half of the patients had fertility preservation discussed or carried out.

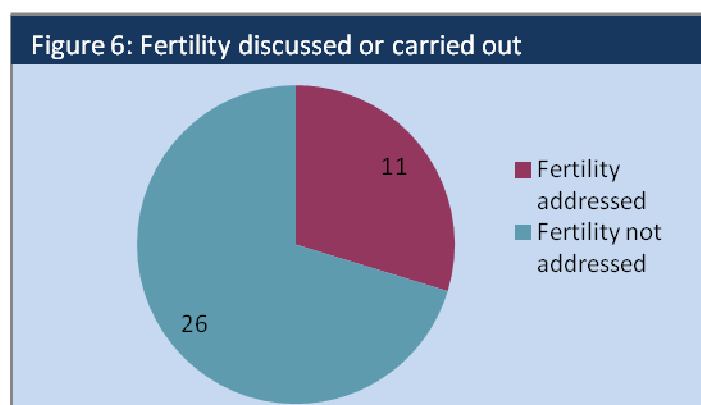


Figure 7 highlights clinical trial enrolment. This appears to be extremely low throughout the entire SMICS region audited.

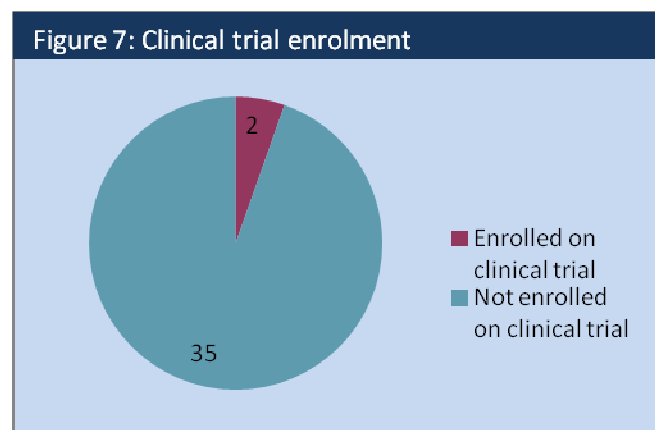
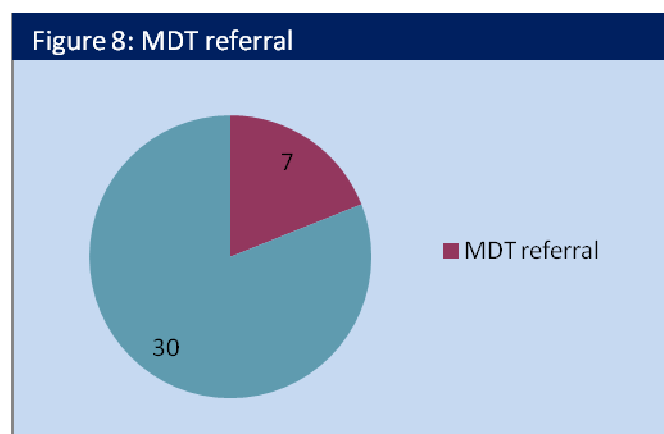


Figure 8 indicates that only seven patients out of 37 were referred to an MDT.



***You Can Training* questionnaire results**

The You Can training was delivered to all 17 stakeholders. A total of 17 questionnaires were completed and returned.

Question 1

Question one asked the stakeholders to rate aspects of the training session including;

- overall quality of the educational components as a learning experience
- opportunity to ask questions
- appropriateness of the length of the program to the amount of material covered

70% responded with 'Good', 18% with 'Excellent', whilst 12% answered 'Adequate'.

Question 2

Question two asked the stakeholders to measure if aims of the education session were met. This was done by rating their understanding of the background and rationale for the development of the You Can AYA psychosocial care manual and their understanding in how to complete an AYA screening tool, develop a care plan and complete an assessment

in accordance with the developmental framework - 60% answered 'Good', whilst 40% said 'Excellent'.

Question 3

Question three required rating the two onTrac@PeterMac facilitators, who delivered this training session. Half of the participants rated the facilitators as 'Good' and the other half as 'Excellent'.

Question 4

Question four asked stakeholders to rate the facility where the training took place. This is not applicable to this report.

Question 5

Question five invites the stakeholder to provide comments on the most valuable point they will take away from this training session. Some response included:

- Gave me a good understanding of onTrac@PeterMac and pilot programme
- Acknowledging service gap and how to identify 'at risk' 15-25 years
- Understanding AYA and how to complete screening tool and care plan
- Developing an understanding of AYA services in general
- Seeing the tools
- Good to know onTrac@PeterMac picks up on gaps in services at Southern Health.
- Good to formalise or flag a secondary consultation follow-up and screening
- There are very specific issues for young people with cancer, I plan to use the care plan to guide all of my assessments not just specifically to this age group
- A clearer understanding of the screening tool and care plan as a complete and working process
- The need to conduct a thorough assessment – clarification of topics was very useful
- To work with social worker in my institution who is also trained and how we will approach this together
- Assessment process

Question 6

Question six asked stakeholders to list the changes they will make in their practice based on what they learnt from the training. Responses included:

- Will use screening tool for AYAs in future
- It has actually made me think twice about how to improve and complete more thorough assessments even with non-AYA patient groups. It has equipped me to assess this patient group in the future
- Our team will work together to initiate programme
- Yes but need to change team process/procedure
- Incorporate this program into the organisation
- Will refer young person to AYA support worker
- Use of tools
- Information a little bit drawn-out as a lot of it is self explanatory and formalises what we do in practice already (re: referrals and providing information). Whether it required 4hrs of training today
- It has made me consider issues that I would not have previously considered such as the importance of education, employment and peer relations.
- Approach my younger patients with more of an ongoing process in mind instead of a one off
- I will attempt to be more thorough in conducting an assessment
- We didn't technically have a written plan due to low numbers, but now have something to implement and follow – is great

- Explore issues/needs/risks in more detail with patients

Question 7

Question seven invited the stakeholders to suggest any areas they would specifically like to see addressed in future Adolescent & Young Adult cancer care forums. Responses included:

- Dealing with death and dying with young people
- Regression ... and empowering young people
- I think a lot has been covered, but resources and support group available to this group is imperative – who, when, why to refer to outside services would be great
- Resources available
- The list of outside agencies that are available for this age group will be very valuable
- What supports are/can be put in place
- Practical strategies re NOW compliance
- It would be useful to have a one page summary or timeline of when screening, follow-ups and assessments are due
- Sexuality
- More clarification around the HEADSS psychosocial frame work.
- Opportunity to work on a case study and fill in assessment
- Would be great to know about what support services are out there for AYAs so we can implement similar strategies to onTrac@PeterMac
- Resources available to support them
- Resource diary – if different service providers put together in alphabetical order supports/resources available for their areas and then information to categorised to create a resource pack for all

Question 8

Question eight called for additional comments which included:

- Very informative and helpful introduction to AYA psychosocial screening – Thank-you!
- Poor slides – unable to read, too much information on all slides
- Sometimes it may be challenging to find the time to carry out complete assessments in practice
- Facilitators coped well with difficult environment (noise level). Facilitators very engaging and open to questions
- Very informative, thank-you, only complaint would be that it is a lot of information in a short time. Otherwise great!
- Perhaps the workshop could be slightly shorter – 4hrs is a long time to sit and listen. Content was very good however I do realise it is difficult to cull the program
- Great!
- Good training

Fertility education forum questionnaire results

The fertility education forum was delivered to 70 healthcare professionals throughout SMICS public member hospitals. 60 questionnaires were completed and returned.

Question 1

Question one requires the participant to rate how well they felt the list of five learning objectives were met. The first learning objective was 'To promote the COSA guidelines *Fertility Preservation for AYAs diagnosed with cancer: Guidance for health professionals* and how to access them'. Half of the participants responded with 'Good', whilst the other half 'Excellent'.

The second objective was 'To provide information about the effect of cancer treatments on fertility'. 56% responded with 'Excellent', 43% answered 'Good', whilst 1% rated this objective as 'Adequate'.

The third objective was 'To provide information on fertility preservation options for young males and females'. 75% of healthcare professionals rated this as 'Excellent' and 25% rated it as 'Good'.

The fourth objective was 'To promote the importance of a timely fertility preservation discussion with cancer patients prior to the commencement of treatment'. 80% thought this was 'Excellent' and 15% as 'Good', while only 5% rated it as 'Adequate'.

The last objective to be rated was 'To enable health care professionals to gain knowledge and confidence in discussing fertility preservation with young cancer patients'. 67% thought this as 'Excellent', 32% as 'Good', and 1% as 'Adequate'.

Question 2

Question two asked the healthcare professional to rate the quality of the VARTA presenter, which resulted in 78% responding 'Excellent' and 22% responding as 'Good'.

Question 3

Question three invited the healthcare professionals to list the most valuable point that they would take away from the fertility forum. Some responses included:

- Permanent care alternatives
- Being aware of the different options available for patients
- To ensure that each AYA patient has been spoken to about fertility
- Female preservation and options
- The importance of documenting the discussions with patients irrespective of outcomes
- Never rule out fertility options for women
- All invaluable available resources that I wasn't previously familiar with
- The resources available for health professionals to access
- Freezing embryos – options for women
- How successful sperm freezing is
- How important fertility discussions are
- Awareness options available to patients and how to access this info
- Essential to ensure patients are informed of all infertility issues and options
- The need to address topic early!
- To have relevant accurate and up to date information available to inform patients
- Lots of options to inform patients and how to talk about it
- Awareness
- Infertility due to chemo/radiation therapy. Education is compulsory
- To make sure the issue of fertility has been raised/discussed with patients with oncologist or when starting treatment

Question 4

Question four invited the healthcare professional to make any additional comments following the completion of the fertility forum. Some additional comments were:

- Thank you so much. Great that we do it with males a lot but not women's fertility
- Great refresher – very important issues
- Well done – certainly informative and worthwhile
- Permanent care – 'not the same as adoption' – child can be returned to the parent

- Information was well presented and Kate was very informative
- Very informative, simple and relevant
- Thank you! Very informative and relevant – would love to learn more!!!!
- When educating patients about fertility options are people given information about what happens if they don't survive and those implications?
- I am interested in learning more about this to help my clients
- Excellent, informative – really kept my interest!!

Service Mapping - Identification of local psychosocial support services

SMICS cancer service mapping identified that Alfred Health is the only service that has specialised psychology access. There is no allocated psychology service for cancer patients at Peninsula Health or Southern Health. Southern Health does have limited access to a psychiatrist. Cabrini Health has a psycho-oncologist in private practice for outpatient consultation.

Due to limited access to psychology in SMICS health services, this identifies a gap in AYA psychosocial support services. After mapping the southern Melbourne region for psychology services available for AYA's, *headspace Southern Melbourne* was approached. *headspace Southern Melbourne* has been set up to help young people aged 12-25 and offer them access to a range of youth-friendly health professionals who can help with; mental health and counseling, alcohol & other drug services, general health, and education and employment opportunities along with other services.

SMICS originally met the headspace Southern Melbourne manager to discuss the YCN project, and consequently a meeting was organised with *headspace Southern Melbourne*, to introduce staff from the onTrac@PeterMac service. An agreement was made with *headspace Southern Melbourne* to receive referrals from SMICS member hospitals to help the establishment of a sustainable model of care and referral pathway that promote optimal care and provides comprehensive psychosocial support for AYA's diagnosed with cancer. onTrac@PeterMac will act as a secondary consultation service for headspace if required.

Developing and strengthening linkages between local clinicians and OnTrac@PeterMac

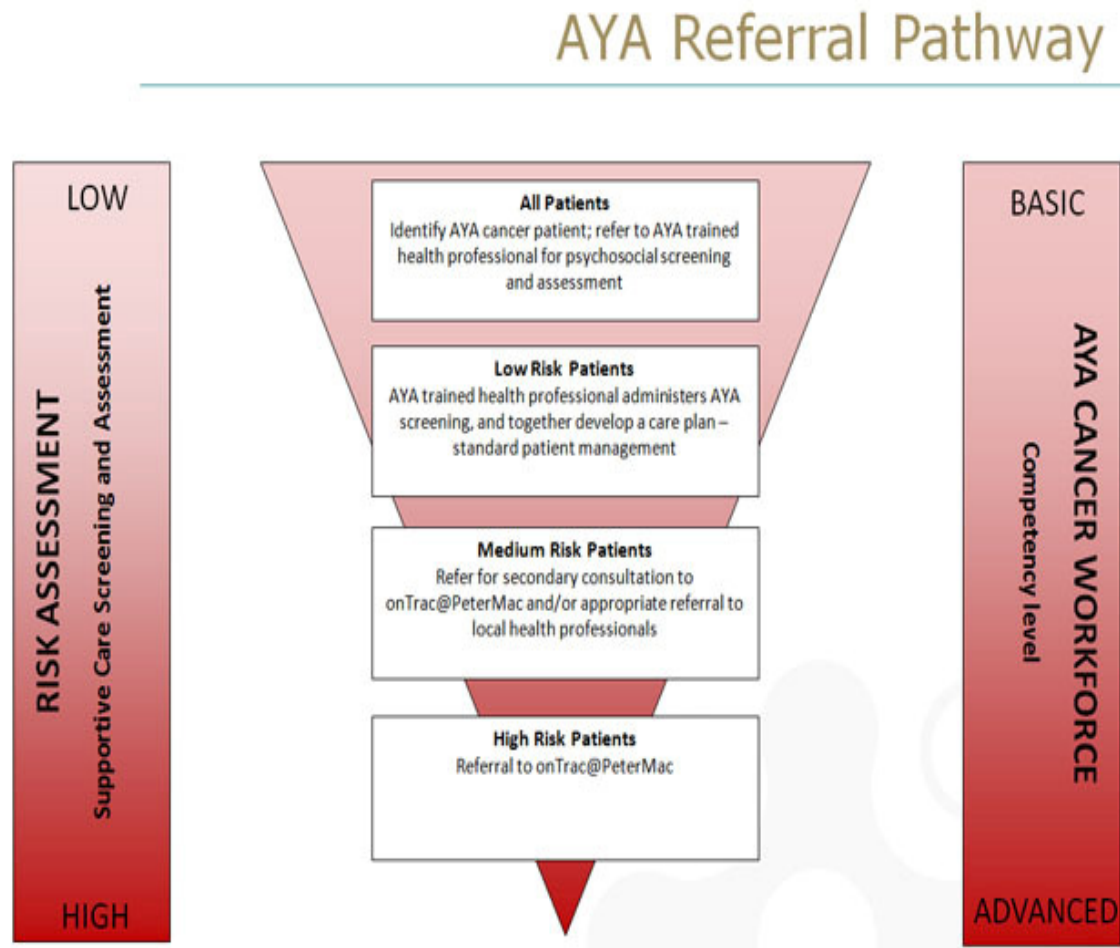
Since the introduction of the YCN project there have been nine referrals from SMICS health services to the onTrac@PeterMac secondary consultation service. It is hoped that as many young people as possible can be identified, discussed and supported via this psychosocial secondary consultation service. This meeting provides an opportunity for healthcare professionals to discuss current AYA patients and their unique psychosocial requirements and where appropriate seek advice and guidance on additional supports available.

Four of the nine referrals from the SMICS region were presented in person at the onTrac@PeterMac secondary consultation meeting. This not only helps build relationships between the two providers, but also improves linkages between oncology health professionals across Victoria. The project has networked extensively with local clinicians to promote the services of onTrac@PeterMac and assisted in guiding and influencing referral and presentation of local AYA's at the onTrac@PeterMac secondary consultation meeting.

Achievement of project aims

Model of care

Within SMICS public health services, SMICS has developed and piloted a model of care that could be sustainable for the future. The diagram below displays this model.



In support of the methodology and findings of the Project, this model has been developed to facilitate direct referral to an AYA trained health professional for psychosocial screening and assessment once an AYA has been identified by a staff member. The trained health professional administers the screening tool, and together with the AYA, develop a care plan.

If the AYA is screened as low risk or having normal levels of distress, they may be managed through standard procedures at the local health service. If the AYA is screened as medium risk, they may require a referral to an appropriately advanced AYA trained health professional, such as onTrac@PeterMac or headspace, for further support. If the patient is screened as high risk, they should be referred directly to onTrac@PeterMac, as they are currently the only Victorian multi-disciplinary AYA focused clinical care team, renowned for providing best-practice care to the specific AYA oncology population.

Next steps

- SMICS plan to liaise with onTrac@PeterMac to offer further training to project stake holders, and individual training to new health professionals
- SMICS will incorporate AYA training into its supportive care calendar
- They will continue to offer support in sustaining the relationships with local health professional and other organisations that are skilled in AYA care
- SMICS will continue to provide this guidance and continue to influence AYA referrals to the onTrac@PeterMac secondary consultation meeting
- As part of the Supportive Care portfolio SMICS will monitor the referral process between local health sites psychosocial support access, inclusive of headspace
- As part of the Supportive Care portfolio SMICS will audit results of supportive care screening including You Can screening

Appendices

REFERRAL PATHWAYS PROJECT

The aim of this medical record audit is to identify referral pathways within Southern Melbourne Integrated Cancer Service (SMICS) and between SMICS and other Integrated Cancer Services (ICS).

The purpose of collecting this information is to:

- * Identify current pathways of referrals across for the adolescent and young adult (AYA) cancer population within SMICS member health services
- * Identify the rationale for existing linkages and referral pathways
- * Gain an impression of health service capacity resulting from pathways used (i.e. over/under utilisation)
- * Identify best practice regarding referral pathways for those AYAs affected by cancer, across all tumour streams
- * Improve referral pathways for AYAs affected by cancer across SMICS.

The questionnaire consists of seventeen questions divided into four sections:

SECTION 1 relates to patient demographics, information about the type of cancer, the date of diagnosis and the length of time from diagnosis to the first appointment

SECTION 2 aims to capture information about referrals, treatment sites and settings and communication between treating team members

SECTION 3 aims to elicit information about multidisciplinary team referral, the stage of treatment when the patient was discussed and how the clinician/s participated in the multidisciplinary discussion

SECTION 4 examines what general practitioner (GP) referral information is filed in the medical record.

The AYA medical records to be included are those treated within the calendar year of 2009.

At the completion of data entry into each page, press the NEXT button to save the information and progress the survey to the following page. If you are unable to complete the audit in a single sitting, you can return at a later time to enter further information. All information entered prior to pressing the NEXT button will be saved.

Once the survey is completed, please press the DONE button and all data will be saved.

A separate survey is to be commenced for each medical record.

Lisa Brady

Youth Cancer Network project officer, SMICS

This section seeks the following information:

- * Patient demographics
- * Information about the type of cancer
- * The date of diagnosis
- * The length of time from diagnosis to the first appointment

*1. Please choose the survey number. Once you have allocated the number, please complete the separate excel worksheet that provides the patient MR number with the survey number e.g. survey 10 = MR number 12345

	Number
Survey number	<input type="text"/>

*2. Please select the patient age, gender, residential postcode and disease status

	Age	Gender	Residential postcode	Disease status
Demographic details	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

3. Please describe the nature of the cancer diagnosis for this episode

- ☐ New primary cancer
- ☐ New synchronis cancer
- ☐ Recurrence of disease
- ☐ Metastatic disease
- ☐ Other - please describe

Other (please specify)

*4. What is the site of the patient's primary and metastatic cancer/s and to which tumour stream is the cancer categorised?

	Cancer type/site - primary (this episode only)	Tumour group - primary (this episode only)	Metastatic cancer (this episode only)
Cancer - primary (this episode only)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Cancer - other primary (this episode only)	<input type="text"/>	<input type="text"/>	<input type="text"/>

Other, including previous cancer history and/or a significant family history (please specify)

5. What was the length of time from when the patient experienced first signs of symptoms, until seeking medical advice/review?

- ☐ Less than 1 week
- ☐ 1-2 weeks
- ☐ 2-3 weeks
- ☐ 3-4 weeks
- ☐ 1-2 months
- ☐ 2-3 months
- ☐ 3-4 months
- ☐ 5-6 months
- ☐ Greater than 6 months

***6. What date was the patient first diagnosed for this episode -the first date that cancer was diagnosed by pathology?**

DD MM YYYY

Date of diagnosis / /

***7. What was the length of time from when the patient (suspected, diagnosed or with recurrence) was referred to the health service/specialist clinician, to their first appointment?**

- ☐ 1 - 7 days
- ☐ 1 week
- ☐ 2 weeks
- ☐ 3 weeks
- ☐ 4 weeks
- ☐ 5 weeks
- ☐ 6 weeks
- ☐ 8 weeks
- ☐ 10 weeks
- ☐ Other - please state how long in the text box below
- ☐ Unknown

Other - please specify how long

8. Please describe the contributing factors if the length of time is greater than:

*Immediately for acute leukaemia and non-hodgkin's lymphoma

*two weeks for hodgkin's lymphoma

*two weeks for testicular cancer

*twenty-four hours for significant symptoms indicative of a malignant CNS tumour, or one week for non-specific symptoms

*one week for sarcoma patients.

9. Who referred the patient to the specialist clinician/health service and where was the patient seen after this referral? Please make only one selection (primary or public or private sector).

	Referring clinician	Sector where the patient was seen after first referral
Clinician in the primary sector	<input type="text"/>	<input type="text"/>
Clinician in public sector	<input type="text"/>	<input type="text"/>
Clinician in private sector	<input type="text"/>	<input type="text"/>

Other/ Unknown (please specify)

This section aims to capture information about:

*** Referrals**

*** Treatment sites and settings**

*** Communication between treating team members**

***10. Mapping the patient pathway: please select the clinician/group seen by the patient at each of the relevant appointments. Please make a selection for every appointment attended by the patient. In the case of follow-up appointments, please identify the health professional and the date of the first appointment only.**

NB the date of each appointment is to be recorded in the following question

Appointment with:

Primary sector
appointment 1 (GP,
Community Health Nurse)

Primary sector
appointment 2 (GP,
Community Health Nurse)

Primary sector
appointment 3 (GP,
Community Health Nurse)

Primary sector
appointment 4 (GP,
Community Health Nurse)

Primary sector
appointment 5 (GP,
Community Health Nurse)

Diagnostic appointment 1

Diagnostic appointment 2

Diagnostic appointment 3

Diagnostic appointment 4

Diagnostic appointment 5

Staging procedure 1

Staging procedure 2

Staging procedure 3

Staging procedure 4

Specialist appointment 1

Specialist appointment 2

Specialist appointment 3

Specialist appointment 4

Specialist appointment 5

Specialist appointment 6

Multidisciplinary meeting

1

Multidisciplinary meeting 2	<input type="text"/>
Multidisciplinary meeting 3	<input type="text"/>
Multidisciplinary meeting 4	<input type="text"/>
Treatment - neo-adjuvant chemotherapy	<input type="text"/>
Treatment - neo-adjuvant radiotherapy	<input type="text"/>
Treatment - surgery 1	<input type="text"/>
Treatment - surgery 2	<input type="text"/>
Treatment - surgery 3	<input type="text"/>
Treatment - surgery 4	<input type="text"/>
Treatment - chemotherapy - enter commencement date in far right column	<input type="text"/>
Treatment - chemotherapy - enter completion date in far right column	<input type="text"/>
Treatment - radiotherapy - enter commencement date in far right column	<input type="text"/>
Treatment - radiotherapy - enter completion date in far right column	<input type="text"/>
Treatment/procedure 1 (e.g. blood transfusion or treatment for febrile neutropenia)	<input type="text"/>
Treatment/procedure 2	<input type="text"/>
Treatment/procedure 3	<input type="text"/>
Treatment/procedure 4	<input type="text"/>
Treatment/procedure 5	<input type="text"/>
Treatment/procedure 6	<input type="text"/>
Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/>

Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/>
Appointment/referral - ontrac@petermac	<input type="text"/>
Appointment - specialist nurse/nurse coordinator 1	<input type="text"/>
Appointment - specialist nurse/nurse coordinator 2	<input type="text"/>
Appointment - specialist nurse/nurse coordinator 3	<input type="text"/>
Appointment - specialist nurse/nurse coordinator 4	<input type="text"/>
Appointment - specialist nurse/nurse coordinator 5	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical,	<input type="text"/>

psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/>
Appointment - follow-up 1	<input type="text"/>
Appointment - follow-up 2	<input type="text"/>
Appointment - follow-up 3	<input type="text"/>
Appointment - follow-up 4	<input type="text"/>
Appointment - follow-up 5	<input type="text"/>
Appointment - follow-up 6	<input type="text"/>
Appointment - follow-up 7	<input type="text"/>
Appointment - follow-up 8	<input type="text"/>
Appointment - follow-up 9	<input type="text"/>
Appointment - follow-up 10	<input type="text"/>
Palliative care - pain control	<input type="text"/>

Palliative care - home
based

Palliative care -
hospice/hospital based

Other - please state the type of appointment/s or treatment/s, who the appointment/treatment was with and the date of the appointment

***11. Please note the date of each diagnostic test, appointment, treatment and follow-up appointment for which you provided a response in the previous question**

	DD	MM	YYYY
Primary sector appointment 1 (GP, Community Health Nurse)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Primary sector appointment 2 (GP, Community Health Nurse)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Primary sector appointment 3 (GP, Community Health Nurse)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Primary sector appointment 4 (GP, Community Health Nurse)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Primary sector appointment 5 (GP, Community Health Nurse)	<input type="text"/>	<input type="text"/>	<input type="text"/>
Diagnostic appointment 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Diagnostic appointment 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
Diagnostic appointment 3	<input type="text"/>	<input type="text"/>	<input type="text"/>
Diagnostic appointment 4	<input type="text"/>	<input type="text"/>	<input type="text"/>
Diagnostic appointment 5	<input type="text"/>	<input type="text"/>	<input type="text"/>
Staging procedure 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Staging procedure 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
Staging procedure 3	<input type="text"/>	<input type="text"/>	<input type="text"/>
Staging procedure 4	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 3	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 4	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 5	<input type="text"/>	<input type="text"/>	<input type="text"/>
Specialist appointment 6	<input type="text"/>	<input type="text"/>	<input type="text"/>
Multidisciplinary meeting 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Multidisciplinary meeting 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
Multidisciplinary meeting 3	<input type="text"/>	<input type="text"/>	<input type="text"/>
Multidisciplinary meeting 4	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - neo-adjuvant chemotherapy	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - neo-adjuvant radiotherapy	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - surgery 1	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - surgery 2	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - surgery 3	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - surgery 4	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - chemotherapy - enter commencement date	<input type="text"/>	<input type="text"/>	<input type="text"/>
Treatment - chemotherapy - enter completion	<input type="text"/>	<input type="text"/>	<input type="text"/>

date	
Treatment - radiotherapy - enter commencement date	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment - radiotherapy - enter completion date	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 1 (e.g. blood transfusion or treatment for febrile neutropenia)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 2	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 3	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 4	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 5	<input type="text"/> / <input type="text"/> / <input type="text"/>
Treatment/procedure 6	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness not cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Acute illness cancer treatment related (please describe in text box below)	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment/referral - ontrac@petermac	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - specialist nurse/nurse coordinator 1	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - specialist nurse/nurse coordinator 2	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - specialist nurse/nurse coordinator 3	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - specialist nurse/nurse coordinator 4	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - specialist nurse/nurse coordinator 5	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>

Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - supportive care - physical, psychological, social, spiritual, information, school/education/vocation	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 1	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 2	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 3	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 4	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 5	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 6	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 7	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 8	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 9	<input type="text"/> / <input type="text"/> / <input type="text"/>
Appointment - follow-up 10	<input type="text"/> / <input type="text"/> / <input type="text"/>
Palliative care - pain control	<input type="text"/> / <input type="text"/> / <input type="text"/>
Palliative care - home based	<input type="text"/> / <input type="text"/> / <input type="text"/>
Palliative care - hospice/hospital based	<input type="text"/> / <input type="text"/> / <input type="text"/>

* 12. To whom, for what reason and at what stage was the patient referred?				
	Referred yes/no	Reason for referral	Stage of referral	Length of time to first appointment
Dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fertility Specialist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genetics counsellor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lymphoedema practitioner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical haematologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medical oncologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multidisciplinary team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nurse specialist e.g. haem/oncology nurse-coordinator/breast care nurse/stomal therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occupational therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ontrac@petermac	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pain team	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care nurse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pastoral Care Worker	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pathologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Plastic surgeon	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psycho-oncologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Radiation oncologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
Radiologist	<input type="text"/>	<input type="text"/>	<input type="text"/>
School/Education advisor	<input type="text"/>	<input type="text"/>	<input type="text"/>
Social worker	<input type="text"/>	<input type="text"/>	<input type="text"/>
Support group	<input type="text"/>	<input type="text"/>	<input type="text"/>
Other (please specify)	<div style="border: 1px solid black; height: 100px; width: 100%;"></div>		

13. This question is seeking information about the sector in which the patient received treatment/care & or was discussed at a multidisciplinary meeting. Please select the type of care/treatment/discussion, then select the sector.

	Setting/sector
Presentation to GP, Community Health Nurse, Women's Health Nurse	<input type="text"/>
Diagnostic pathology	<input type="text"/>
Diagnostic radiology	<input type="text"/>
Specialist appointment 1	<input type="text"/>
Specialist appointment 2	<input type="text"/>
Multidisciplinary meeting 1	<input type="text"/>
Multidisciplinary meeting 2	<input type="text"/>
Multidisciplinary meeting 3	<input type="text"/>
Multidisciplinary meeting 4	<input type="text"/>
Neo-adjuvant chemotherapy	<input type="text"/>
Neo-adjuvant radiotherapy	<input type="text"/>
Pre-admission appointment	<input type="text"/>
Surgery 1	<input type="text"/>
Surgery 2	<input type="text"/>
Surgery 3	<input type="text"/>
Surgery 4	<input type="text"/>
Clinical trial	<input type="text"/>
Chemotherapy	<input type="text"/>
Radiotherapy	<input type="text"/>
Appointment with nurse/nurse coordinator/specialist	<input type="text"/>
Physiotherapy	<input type="text"/>
Occupational therapy	<input type="text"/>
Rehabilitation	<input type="text"/>
Lymphoedema therapy	<input type="text"/>
Supportive care - social	<input type="text"/>

work	
Supportive care - psychology/counselling	<input type="text"/>
Supportive care - psycho-oncology	<input type="text"/>
Supportive care - pastoral care	<input type="text"/>
Supportive care - dietitian	<input type="text"/>
Supportive care - school/education	<input type="text"/>
Genetic counselling	<input type="text"/>
Follow-up care 1	<input type="text"/>
Follow-up care 2	<input type="text"/>
Follow-up care 3	<input type="text"/>
Follow-up care 4	<input type="text"/>
Follow-up care 5	<input type="text"/>
Follow-up care 6	<input type="text"/>
Pain control care	<input type="text"/>
Palliative care	<input type="text"/>
End of life care	<input type="text"/>
Other: please describe	<input type="text"/>
Other (please specify)	<div style="border: 1px solid black; height: 50px; width: 100%;"></div>

14. Was the patient offered the opportunity to participate in a clinical trial? If so, did the patient elect to participate in the trial?

Please enter the trial name in the free text box.

Yes

No

Was the patient
offered to participate
in a clinical trial?

Other (please specify)

***15. In which ICS did the patient receive the majority of their treatment planning, treatment and care?**

Integrated cancer service

Primary ICS

Other ICS

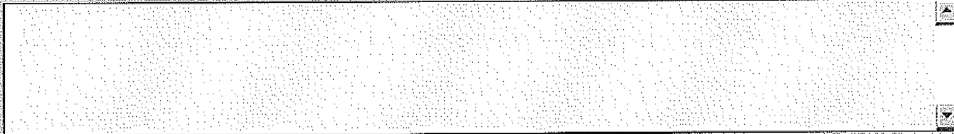
Other (please specify)

16. At what stage did communication occur with the GP, members of the multidisciplinary team and other clinicians regarding the diagnosis, treatment, end of treatment, supportive care requirements and ongoing needs of the patient?

	General practitioner	Surgeon	Physician	Medical Haematologist	Medical oncologist	Radiation oncologist	Fertility specialist	Allied health	Other clinicians (please describe in text box below)
If the patient did not attend the first or subsequent specialist appointment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
After the initial and subsequent specialist appointment/s	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Before a multidisciplinary meeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At a multidisciplinary meeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
After a multidisciplinary meeting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When the treatment plan was decided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When the patient required supportive care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When coordination of care was required	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
During the patient's treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If there was a change in treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
At the completion of treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When the follow-up plan was developed and documented	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When/if the cancer recurred or progressed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Palliative care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
For end of life care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other times (please	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

describe in the text
box below)

Other: please describe



The next two questions relate to multidisciplinary team discussion and specifically seek information about:

- * **Referral to a multidisciplinary team for treatment and care planning**
- * **Communication of MDT recommendations.**

17. Is there evidence that the patient was referred to a multidisciplinary team for discussion and development of treatment/management/care recommendations?

- ☐ Yes
- ☐ No - please skip the next question and go to SECTION 4

18. How were the MDT recommendations communicated to the GP, members of the multidisciplinary team and other clinicians? Multiple responses can be entered if communication occurred by more than one means.

	Verbal communication at the MDT meeting	Documentation in the medical record	Telephone call after the MDT meeting	Letter after the MDT meeting	Fax after the MDT meeting	Email after the MDT meeting	Documentation in a secure clinical management system or database accessible by all multidisciplinary team members
GP	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Multidisciplinary team members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other clinicians	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)							

The final two questions relate to the initial referral from the GP to the specialist or health service.

***19. Was an initial letter of referral from the GP filed in the medical record?**

- ☐ Yes - please answer question 17
- ☐ No - please complete the survey and press the done button.

20. What information was included in the referral letter from the GP to the specialist or public health service?

	Yes/no
Relevant past history	<input type="text"/>
Current history	<input type="text"/>
Family history	<input type="text"/>
Examination	<input type="text"/>
Investigations/diagnostic tests	<input type="text"/>
Social issues	<input type="text"/>
Current medications	<input type="text"/>

Appendix 2



onTrac@PeterMac
VIC TREATING ADOLESCENT & YOUNG ADULT CANCER SERVICE

Adolescent & Young Adult Oncology Training Session: Psychosocial Screening & Assessment EVALUATION

Name (optional): _____

Health Service: _____

Aims of the day:

1. Understand the background and rationale for the development of the AYA psychosocial care manual
2. Understand how to complete AYA screening, develop a care plan and complete an assessment in accordance with the developmental framework
3. Have an opportunity to apply this process to relevant cases
4. Have an opportunity to explore how this framework may be implemented in specific institutions

Question 1. (Please tick)

Please rate the following aspects of the program	Poor	Adequate	Good	Excellent
Overall quality of the educational components as a learning experience	1	2	3	4
Opportunity to ask questions	1	2	3	4
Appropriateness of the length of the program to the amount of material covered	1	2	3	4

Question 2. (Please tick)

Measurement of met aims of the forum: Please rate	Poor	Adequate	Good	Excellent
Understand the background and rationale for the development of the AYA psychosocial care manual	1	2	3	4
Understand how to complete AYA screening, develop a care plan and complete an assessment in accordance with the developmental framework	1	2	3	4
Have an opportunity to apply this process to relevant cases	1	2	3	4
Have an opportunity to explore how this framework may be implemented in specific institutions	1	2	3	4

Question 3. (Please tick)

Please rate the quality of today's facilitators	Poor	Adequate	Good	Excellent
Felicity Sleeman	1	2	3	4
Christina Portelli	1	2	3	4

PTO... |

Question 4. (Please tick)

Please rate the facilities & organisation of the forum:	Poor	Adequate	Good	Excellent
Suitability of venue				
Catering				
Comfort / breaks				
Overall organisation				

5. What was the most valuable point that you will take away from today's forum?

6. Are there any changes you will make in your practice based on what you have learnt today?

7. Are there any areas you would specifically like to see addressed in future Adolescent & Young Adult cancer care forums?

8. Additional comments:

Thank you for your time in completing this evaluation

Appendix 3



INFORMATION ON FERTILITY AND CANCER

Purpose of Information:

To provide information and resources regarding fertility management for patients diagnosed with cancer and their family/carers. *It is important to note that this information cannot account for individual differences among patients. The information is not intended to replace clinician judgement.*

Definition of infertility:

Infertility is usually defined as the failure to conceive after 12 months of regular unprotected intercourse or the inability to carry a pregnancy to live birth.¹

Cancer and infertility:

Many cancers that present in people of child bearing age can be successfully treated. Unfortunately infertility or sub-fertility is a significant and distressing effect of cancer treatment for many survivors of cancers.²

In many cases fertility preservation is possible. To optimise outcomes for young patients, timely and full discussion of risks, fertility preservation options and related issues are essential.²

- Oncology specialists seeing patients for the consideration of cancer treatment should address potential treatment-related infertility and explore fertility options with them, (and in the case of children, with their parents) PRIOR to initiating treatment.²
- Patients should be given the option of having family/carer present for the discussion.²

General Information for Health Professionals:

Clinical Oncological Society of Australia (COSA) Fertility preservation for Adolescents and Young Adults (AYA's) diagnosed with cancer: Guidance for health professionals -

http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation

Cancer Council Victoria - <https://www.cancervic.org.au/>

Fertility clinics in Victoria - <http://www.varta.org.au/registered-art-providers-clinics/w1/i1003340/>

General Information and resources for Patients:

Maybe Later Baby: A guide to fertility for young people with cancer -

<http://www.nowwhat.org.au/about/resources/maybe-later-baby-a-guide-to-fertility-for-young-people-with-cancer>

'Just take it day to day: A guide to surviving life after cancer' DVD and booklet available (Peter Mac)

<http://www.petermac.org/cancersurvivorship/JustTakeItDaytoDayVideos>

1. The Fertility Society of Australia Homepage. See <http://www.fertilitysociety.com.au/>.

2. http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation

INFORMATION ON FERTILITY AND CANCER

Male patients with Cancer

Many of the therapies recommended for the most common cancers have the potential to cause impaired fertility in the short or long term. For males, the major cause of impaired fertility is chemotherapy, or radiation-induced damage to sperm.²

Impact of cancer treatments on male reproductive and hormonal functions and the effect of cancer treatments on sperm production in males please access:

[http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Impact of cancer treatments on fertility/Male reproductive and hormonal functions](http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Impact_of_cancer_treatments_on_fertility/Male_reproductive_and_hormonal_functions)

Fertility preservation options for males please access:

[http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Options for fertility preservation](http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Options_for_fertility_preservation)

Sperm Cryopreservation:

- Sperm cryopreservation **PRIOR** to initiation of treatment is strongly recommended.²
- Every effort should be made to collect sperm **PRIOR** to treatment because the quality of the sample and DNA integrity may be compromised after a single treatment.²

Fertility Counselling:

- A referral for fertility counselling is an important consideration (**before, during or after** cancer treatment) to discuss semen quality, implications and/or future prospects for fertility.²
- All patients and their families should also be offered psychosocial support.²

Fertility Information for patients:

- Health professionals involved in the care of patients with cancer should provide information (*verbal and written*) about fertility risks, preservation options and related issues in a clear and direct manner.²

Patient information and resources:

'Can I still have children? Fertility options for young men having chemotherapy and radiotherapy' link:

<http://www.mivf.com.au/ivf/upload/file/Fertility-preservation-Can%20I%20For%20men.pdf>

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Fertility/Fertilityinmen.aspx>

For sperm cryopreservation estimated costs, fertility specialists and counselling services contact:

Monash IVF

www.monashivf.edu.au

Clayton: 95432833

Hawthorn: 94299188

Frankston: 0488483456

Melbourne IVF

www.mivf.com.au/

East Melbourne: 94734444

The Royal Women's Hospital

<http://www.thewomens.org.au/>

Reproductive Services: 83453200

1. The Fertility Society of Australia Homepage. See <http://www.fertilitysociety.com.au/>.
2. http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation

INFORMATION ON FERTILITY AND CANCER

Female patients with Cancer

Many of the cancer therapies recommended for the most common cancers have the potential to cause impaired fertility in the short or long term. For females, the major effect of cancer treatment on reproductive potential is via damage to the ovary and the oocytes with accelerated oocyte depletion. This can result in temporary or permanent ovarian failure and early menopause. Uterine damage is also a complication of pelvic radiotherapy.²

Impact of cancer treatments on female reproductive and hormonal functions and effects of cancer treatments on ovarian function in females please access:

http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Impact_of_cancer_treatments_on_fertility/Female_reproductive_and_hormonal_functions

Fertility preservation options where appropriate for females please access:

http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation/Options_for_fertility_preservation

Fertility Counselling:

- A referral for fertility counselling is an important consideration (before, during or after cancer treatment) to discuss future prospects for fertility, and the options available.²

Fertility Information for patients:

- Health professionals involved in the care of patients with cancer should provide information (verbal and written) about fertility risks, preservation options and related issues in a clear and direct manner.²

Patient information and resources:

'Can I still have children? Fertility options for young women having chemotherapy and radiotherapy' Link:

http://www.mivf.com.au/ivf/upload/file/Fertility-Preservation-Can%20I%20Have_Women.pdf

<http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects/Fertility/Fertilityinwomen.aspx>

Fertility post cancer treatment:

Jean Hailes Foundation- Women's health and menopause services.

<http://www.jeanhailes.org.au/>

Phone: 95626771

Southern Health Menopause Clinic, Monash Medical Centre

Phone: 95942405

Menopause Clinic, The Women's Hospital:

Phone: 83453032

For estimated costs, fertility specialists and counselling services please contact:

Monash IVF

www.monashivf.edu.au

Clayton: 95432833

Hawthorn: 94299188

Frankston: 0488483456

Melbourne IVF

www.mivf.com.au/

East Melbourne: 94734444

The Royal Women's Hospital

<http://www.thewomens.org.au/>

Reproductive Services: 83453200

1. The Fertility Society of Australia Homepage. See <http://www.fertilitysociety.com.au/>.

2. http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation

Appendix 4

Fertility Preservation in Young Cancer Patients

EVALUATION
Tuesday 30th August 2011
Peninsula Health

Name (optional): _____

Position: _____

Aim:

To provide education for health care professionals caring for young people with cancer, raising awareness of the importance of timely fertility preservation discussions with young cancer patients.

Question 1. (Please circle)

Please rate how well you feel the learning objectives were met:	Poor	Adequate	Good	Excellent
To promote the COSA guidelines <i>Fertility Preservation for AYAs diagnosed with cancer: Guidance for health professionals</i> and how to access them	1	2	3	4
To provide information about the effect of cancer treatments on fertility	1	2	3	4
To provide information on fertility preservation options for young males and females	1	2	3	4
To promote the importance of a timely fertility preservation discussion with cancer patients prior to the commencement of treatment	1	2	3	4
To enable health care professionals to gain knowledge and confidence in discussing fertility preservation with young cancer patients	1	2	3	4

Question 2. (Please circle)

Please rate the quality of today's presenter	Poor	Adequate	Good	Excellent
Kate Bourne	1	2	3	4

3. What was the most valuable point that you will take away from today's forum?

4. Additional comments:

Thank you for your time in completing this evaluation

Abbreviations

AYA	Adolescent and Young Adult
COSA	Clinical Oncological Society of Australia
ICS	Integrated Cancer Services
SMICS	Southern Melbourne Integrated Cancer Service
VARTA	Victorian Assisted Reproductive Treatment Authority
VCAP	Victorian Cancer Action Plan
VTYCN	Victorian and Tasmanian Youth Cancer Network
YCN	Youth Cancer Network

References

¹ *National Service Delivery Framework for Adolescents and Young Adults with Cancer.* (2009) Australia: Cancer Australia

² *Victoria's Cancer Action Plan 2008-2011.* Victorian Government Department of Human Services. Melbourne Australia

³ *CanTeen Adolescent and Young Adult oncology Psychosocial Care Manual* (2011) Australia: CanTeen

⁴ *SMICS Service mapping project* (2009) (unpublished report)